



11th International CHARGE Syndrome Conference  
Scottsdale, Arizona 2013

**Scottsdale, Arizona**  
**Fairmont Scottsdale Princess**  
**July 25-28, 2013**

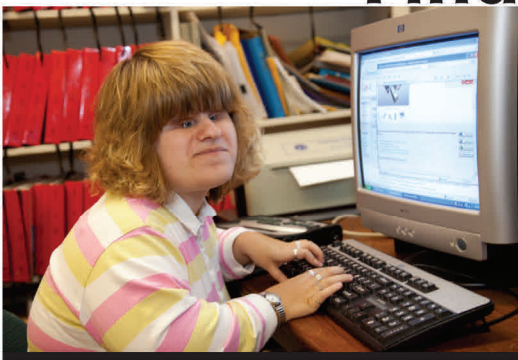
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# 11th International CHARGE Syndrome Conference



*This project is supported (in part) by Perkins School for the Blind, Watertown, Massachusetts through a grant from the Conrad N. Hilton Foundation of Reno, Nevada.*

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**2011 - 2013**

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# Welcome!

## *Experience the Wonder*

Welcome to our 11th International CHARGE Syndrome Conference. Together, we are about to embark on a special journey. Approximately 900 people, including 175 individuals with CHARGE, from 41 states and 10 countries, have gathered here in Arizona to learn, share their experiences and spend time with old and new friends. We come from many different backgrounds, but are all united in our common desire to make a better world for people with CHARGE syndrome.

Whether this is your first conference or your eleventh, I am confident you will find useful information in this quality program. Our presenters have a true passion for CHARGE syndrome. They deserve a special thank you for volunteering their time and sharing their insights and knowledge. We also added more time for parents to share with each other during our parent share sessions. This represents another fabulous opportunity to learn together.

The full conference experience would not be complete without plenty of time to spend with our extended CHARGE families. From the Thursday night reception, to Friday night's dinner and Conference Idol to Saturday's CHARGE-A-Palooza festivities, we will create lasting bonds and memories.

None of this would be possible without the support of our Board, Advisors, members, fundraisers and volunteers. Our program committee, chaired by Marilyn Ogan, put together a top notch program. Thank you all! While this conference was a result of the work of many, a few people have volunteered countless hours over the past 2 years and deserve a special thank you. Our Executive Board of Lisa Weir, Neal Stanger and Brownie Shott, together with Jody Wolfe and Susan Wolfe have committed more hours than I can count to make this Conference the success that it will be. Thank you for your dedication, excellent work, and friendship.

Let's experience the wonder of this conference together.

## **David Wolfe**

David Wolfe  
President and Fundraising Chair  
CHARGE Syndrome Foundation, Inc.

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On behalf of everyone at the CHARGE Syndrome Foundation, we would like to welcome you to Scottsdale, Arizona for the 11th International CHARGE Syndrome Conference. We hope you will be informed, connected, supported and have a wonderful time together with all of the families and professionals who are gathered here for the event.

As you can imagine, putting all of this together is an enormous undertaking so I would like to send a huge THANK YOU to all of the volunteers and contributors who have helped to make this an amazing experience for all of our attendees. We hope you will enjoy experiencing the wonder of the 2013 conference with us.

## **Lisa Weir, Brownie Shott, David Wolfe, Neal Stanger, Jody Wolfe & Susan Wolfe**

Lisa Weir, Conference Chair, Brownie Shott, David Wolfe, Neal Stanger, Jody Wolfe & Susan Wolfe  
2013 Conference Planning Team

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# *Special Thanks*

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Catherine Lacey Photography

### ***Official Conference Videographer***

Sweet Spirit Productions

# *Special Thanks*

## *In-Kind Donors*

**Aaron's**

Provided all of the televisions for the conference



**Badger Balm**

Provided sun screen for conference bags

**Camp Abilities**

Provided Camp Abilities within our camp for all campers



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**Home Depot**

Provided a supervised craft activity in camp



It would be impossible to thank all the wonderful people who have helped us produce this conference, but every effort, big or small, is appreciated. Thanks to all of you for making this a wonderful event!

# 11th International CHARGE Syndrome Conference

# Wednesday, July 24th, 2013

**9am-6pm Conference Registration & Sales Center Open in Palomino Foyer**

**9am-6pm Professional Day Registration in Palomino Foyer**

# Thursday, July 25th, 2013

<b>6:00-6:00</b>	<b><i>Conference Registration &amp; Sales Center Open in Palomino Foyer</i></b>
<b>6:00-12:00</b>	<b><i>Professional Day Registration in Palomino Foyer</i></b>
<b>8:00-12:00</b>	<b><i>Professional Day Conference Morning Sessions in Palomino 1-3</i></b>
<b>12:00-1:00</b>	<b><i>Professional Day Lunch in Palomino 4-5</i></b>
<b>1:00-5:00</b>	<b><i>Professional Day Conference Afternoon Sessions in Palomino 1-3</i></b>
<b>12:00-6:00</b>	<b><i>Camp Discovery &amp; Camp Explorer Registration Open in Princess Ballroom East Foyer</i></b>
<b>7:00</b>	<b><i>Reception in Palomino 4-7</i></b>

## Notes

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# 3rd International CHARGE Syndrome Professional Day

## Thursday, July 25th, 2013

8:00 - 9:00	Breakfast
8:00 - 9:00	Poster Set up
9:00 - 9:15	Welcome and Opening Remarks
9:15 - 9:40	Functions for Chd7, the Gene Altered in CHARGE, in Developing Cells and Tissues - Donna Martin, Joseph Micucci, Ethan Sperry
9:40 - 10:05	Phenotypes in a Drosophila model of CHARGE Syndrome- Daniel R. Marenda
10:05 - 10:30	Epigenetic regulation of neural crest cell development by Brg1 andChd7 - Ching-Pin Chang
10:30 - 11:00	Break
11:00 - 11:25	Chd7 in neural crest-mediated cardiac development - Adam Stein
11:25 - 11:50	Role of CHD7 in Development of Midbrain and Hindbrain - Mark Durham
11:50 - 12:15	Identification of Molecular Markers to Predict Auditory Neuron Function for CHARGE Syndrome - Kelvin Kwan
12:15 - 1:15	Lunch

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# 3rd International CHARGE Syndrome Professional Day

## Thursday, July 25th, 2013

1:15 - 2:30	<p>Poster Presentations</p> <p>Epigenetic regulation of neural crest cell development by Brg1 and Chd7 - Ching-Pin Chang</p> <p>Chd7 in cardiac development - Adam Stein</p> <p>Investigating the Role of CHD7 in Development of the Midbrain and Hindbrain - Mark Durham</p> <p>Identification of Molecular Markers to Predict Auditory Neuron Function for CHARGE Syndrome - Kelvin Kwan</p> <p>The Cerebral Cortex in CHARGE Syndrome- Robert Hevner, Donna Martin</p> <p>Behavior as self-regulatory adaptation, or “I can’t believe my child just did that!”- Tim Hartshorne</p> <p>Why self-stimulation is a good thing, and how and why we should interpret it - David Brown</p> <p>Self-regulatory strategies for children with CHARGE syndrome - Maria Ramirez</p> <p>Getting Ready to Talk to a Psychiatrist - Laurie Denno</p> <p>Information Pack for Practitioners - Gail Deuce</p> <p>Headaches in CHARGE - Tate Jenkins</p> <p>Fathers in CHARGE: Work &amp; Friendships - Shantell Johnson, Kirsten His-song</p> <p>Cognitive Self-regulation in CHARGE Syndrome - Benjamin Kennert</p> <p>Self-regulation of Emotion in CHARGE Syndrome - Benjamin Kennert, Maria Ramirez</p> <p>Models of Conceptualizing Self-regulation in CHARGE Syndrome - Maria Ramirez, Tim Hartshorne</p> <p>Microenterprises - Maria Ramirez, Seraphim Mork, Tim Hartshorne</p> <p>Physiological Self-regulation in CHARGE - Tim Hartshorne, Andrea Larson</p> <p>Understanding Behavioral Self-regulation in CHARGE - Sarah Haney</p>
2:30 - 2:55	The Cerebral Cortex in CHARGE Syndrome - Robert Hevner, Donna Martin
2:55 - 3:20	Gene therapy induces nerve fiber regeneration in the inner ear of a deaf mutant mouse - Yehoash Raphael
3:20 - 3:45	A Study of CHARGE syndrome in the UK - Steve Rose and Simon Howard & Clinical Database - Meg Hefner and Emily Fassi
3:45 - 4:10	Break
4:10 - 4:35	Self-Regulation (3 Part Presentation) - Tim Hartshorne, David Brown, Maria Ramirez
4:35 - 5:00	The clinical overlap between 22q11.2 deletion syndrome and CHARGE syndrome: they are more alike than often anticipated - Nicole Corsten-Janssen
5:00 - 5:25	How to Identify Pain and the Relationship of Pain to Challenging Behavior - Kasee Stratton
5:25 - 5:30	Concluding Remarks

# Friday, July 26th, 2013

7:00-6:00	<i>Conference Registration Open in Palomino Foyer</i>
7:00-6:00	<i>Sales Center Open in Palomino Foyer</i>
7:00-9:00	<i>Breakfast in Palomino Ballroom</i>
7:00-9:00	<i>Camp Discovery &amp; Camp Explorer Registration at Princess Ballroom Foyer</i>
8:00-6:00	<i>Exhibits Open in Palomino Foyer</i>
8:30-11:45	<i>Camp Discovery &amp; Camp Explorer Morning Session in Princess Ballrooms</i>
8:30-11:30	<i>Sib Shop # 1</i>
9:00-9:20	<i>Welcome and Opening Remarks in Palomino Ballroom</i>
9:20-10:20	<i>General Session - Kathy Buckley "Celebrating Abilities"</i>
10:20-10:45	<i>Break</i>
10:45-11:45	<i>Breakout Session #1 - See Next Page for Session Descriptions</i>
11:45-1:00	<b><i>Lunch in Palomino Ballroom</i></b>
12:30-4:45	<i>Camp Discovery &amp; Camp Explorer Afternoon Session</i>
1:00-2:00	<i>Breakout Session #2 - See Next Page for Session Descriptions</i>
2:00-2:15	<i>Break</i>
2:15-3:15	<i>Breakout Session #3 - See Next Page for Session Descriptions</i>
3:15-4:30	<i>Breakout Session #4 - See Next Page- Snacks and Drinks to be Served During Information Central</i>
5:00-6:15	<i>Dinner in Palomino Ballroom 6-10</i>
6:30	<i>3<sup>rd</sup> Annual CHARGE Syndrome "CONFERENCE IDOL" Talent Extravaganza in Palomino 1-5</i>

Notes\_\_\_\_\_

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# Friday, Breakout Sessions

	Breakout Session #1 10:45 - 11:45	Breakout Session #2 1:00 - 2:00	Breakout Session #3 2:15-3:15	Breakout Session #4 3:15-4:30
Palomino 1&2	#1 Sexuality Issues  Stratton	#9 How to Identify Pain  Stratton	#16 Information Central  Posters and Opportunities to Meet With Presenters and Exhibitors  2:45—4:30	
Palomino 3	#2 Physical Education  Lieberman	#10 Balancing the Scales  Lauger		
Palomino 4&5	#3 Genetics Research Updates #1/2  Martin, et al	#11 Genetics Research Updates #2/2  Martin, et al		
Palomino 6&7	#4 A Lot to Swallow  Blake & Beals	#12 Addressing Feeding Difficulties  Pimentel	#17 The Challenge of Mealtimes  Rose, S	
Palomino 8&9	#5 Behavior as Self-regulatory Adaptation  Hartshorne, T	#13 Why Self Stimulation is a Good Thing  Brown	#18 Self- Regulatory Strategies  Ramirez	
Palomino 10	#6 ENT  Choo	#14 We Are in CHARGE  Rose, C	#19 Fathers Forum  Gaudin	
Dorado	#7 CHARGE 101 Diagnosis/Sensory Deficits  Hefner/Davenport	#15 CHARGE 102 Language & Communication  Hartshorne, N	#20 CHARGE 103 Breathing & Anesthesia  Blake	
Moor 1	Young Adult Lounge			
Moor2	Grandparents Gathering			
Arabian	Sib Shops			

# Saturday, July 27th, 2013

7:00-5:00	Conference Registration & Sales Center Open in Palomino Foyer
7:00-9:00	Breakfast in Palomino Ballroom
8:00-2:30	Exhibits Open in Palomino Foyer
8:30-11:45	Camp Discovery & Camp Explorer Morning Session in Princess Ballrooms
8:30-11:30	Sib Shop # 2
9:00-9:15	Welcome and Housekeeping in Palomino Ballroom
9:15-10:15	Foundation General Board Meeting: Reports, Updates and Awards
10:15-10:45	Break
10:45-11:45	Breakout Session #5 - <i>See Next Page for Session Descriptions</i>
11:45-1:00	<b><i>Lunch—In Palomino Ballroom</i></b>
12:30-4:45	Camp Discovery & Camp Explorer Afternoon Session
1:00-4:00	Sib Shop # 3
1:00-2:00	Breakout Session #6 - <i>See Next Page for Session Descriptions</i>
2:15-3:15	Breakout Session #7 - <i>See Next Page for Session Descriptions</i>
3:15-3:30	Break
3:30-4:30	Breakout Session #8 - <i>See Next Page for Session Descriptions</i>
6:30-9:30	CHARGE-A-Palooza: Dinner, Carnival and Silent Auction in Palomino Ballroom

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# Saturday, Breakout Sessions

	Breakout Session #5 10:45 - 11:45	Breakout Session #6 1:00 - 2:00	Breakout Session #7 2:15-3:15	Breakout Session #8 3:30-4:30
Palomino 1&2	#21 Intervener Services Alsop	#28 Technology for Learning and Fun Cooper	#36 Insights on Using the iPad Gil	
Palomino 3	#22 CHARGE and Genetics van Ravenswaaij	#29 Overview of CHARGE and Neurology Constantinou		
Palomino 4&5	#23 The Scoop on Poop Beals	#30 Bone Health Blake & Kirk	#37 Endocrine Problems Kirk	
Palomino 6&7	#24 Peeking Into the Future Bridgeo	#31 Resilient Parenting Hartshorne, T	#38 The Power of Jacob Hartshorne, T et al	#42 Physical Therapy Bushey & Poblete
Palomino 8&9	#25 Preschoolers: Tomorrow's Teens Majors	#32 When Behavior Really is.... Denno	#39 Behavior and Psychiatry Denno & Julian	#43 Making Sense of Behavior Beals
Palomino 10	#26 Special Needs Planning Rhatigan	#33 Intervener Recommendations Gense	#40 They're Not Children Anymore Schwark	#44 Family Leadership Lauger
Dorado	#27 Parent Share: Behavior Stanger & Bixler	#34 Parent Share: Medical Issues Stanger & Bixler	#41 Parent Share: Education Stanger & Bixler	#45 Parent Share: Adult Issues Stanger & Bixler
Moor 1	Young Adult Lounge			
Moor 2		#35 LAMP Words for life Halloran		#46 Fundraising Wolfe
Arabian	Sib Shop			

# Sunday, July 28th, 2013

7:00-9:00	Breakfast in Palomino Ballroom
8:30-12:30	Camp Discovery & Camp Explorer Morning Session in Princess Ballrooms
9:00-9:15	Welcome and Housekeeping in Palomino Ballroom
9:15-9:30	Database Update - Meg Hefner & Emily Fassi
9:30-10:45	Young Adult Panel - Yasmin Farhart, Jason Jones, Paul Khouri and Karlee Ludwig
10:45-11:00	Break
11:00-11:45	Deep Thoughts by David Brown
11:45-12:00	2013 Conference Farewell

# Notes

## **Friday, July 26 - 10:45-11:45 - BREAKOUT SESSION #1**

### **1 - Sexuality Issues for Children and Adolescents with CHARGE - Kasee Stratton - Palomino 1 & 2**

This presentation is important for individuals of ALL AGES. The presentation will highlight the need to establish appropriate social and safe behaviors early (during childhood) regarding the developmental of sexuality. Research will be presented on the need for sexuality education and direct teaching due to high rates of sexual violence against individuals with developmental delay. Topics will include physical examinations, identifying body parts, teaching modesty, how to shower, menstruation, masturbation, and resources for sex education. This presentation has been designed specifically for individuals with CHARGE.

### **2 - Strategies for Involvement in Physical Education & Balance Activities for All - Lauren Lieberman & Pamela Haibach- Palomino 3**

The purpose of this presentation is to share with parents and families the components of a physical education program that will enhance the lives of children with CHARGE Syndrome. The components shared will be 1) The variables necessary to make the best placement decision, 2) The importance of Pre-teaching before each unit, 3) How all nine areas of the Expanded Core Curriculum can be infused into physical education naturally, 4) Training components for paraeducators, 5) Training components for peer tutoring, 6) Instructional strategies (including the use of interpreters if necessary), 7) Resources to share with the physical education team. The resources will include books, videos, web sites, equipment, products, recent research findings, and summer programs that may be available. The last part of the presentation will be a discussion time where parents can share their positive and negative experiences with each other and we as a group can discuss what is working and what we want to change in the future. Our hope it to come up with 3-4 points to add to FamilyConnect (through AFB).

### **3 - Genetics Research Updates Part #1 of 2 - Kelvin Kwan, Robert Hevner, Ching-Pin Chang & Adam Stein - Palomino 4 & 5**

Come learn about all the latest research on CHARGE syndrome from some of the scientists doing that research. Some of the research was funded by the CHARGE Syndrome Foundation. Presentation abstracts are below.

#### **Kelvin Kwan: Identification of Molecular Markers to Predict Auditory Neuron Function in CHARGE Syndrome**

Encased in a bony labyrinth, the cochlea residing within the inner ear allows us to discriminate and hear complex sounds. Hair cells in the cochlea are the sensory cells that convert sound into neural signals, which are then relayed to the brain by auditory neurons. Patients with CHARGE are frequently affected by sensorineural hearing loss resulting from hair cells or auditory neuron dysfunction. Currently, the

only treatment for hearing loss is the use of a cochlear implant or a hearing aid. A major factor for auditory prosthesis candidacy is a functional auditory nerve. Since auditory neuron impairment can vary dramatically in CHARGE, it would be ideal to determine functional activity of neurons from individuals. However, direct recording from the auditory nerve is invasive and difficult because the inner ear is small, encased in bone and difficult to access. Instead, we have established a progenitor cell line that continually proliferates and can differentiate into auditory neurons. I propose to use progenitor-derived auditory neurons as a platform for identifying a panel of genes that correlates to auditory neuron function. In the future, when samples from patients with CHARGE become available, induced pluripotent stem cells (iPSCs) can be made. Auditory neurons generated from iPSCs from patients with CHARGE can be used to determine their candidacy for auditory prosthesis.

### **Robert Hevner: The Cerebral Cortex in CHARGE Syndrome**

CHARGE syndrome is caused in most cases by mutations in CHD7, a gene that is highly expressed in many areas of the developing brain, including the cerebral cortex. The cerebral cortex may develop abnormally in CHARGE syndrome, contributing to cognitive and behavioral problems in some affected individuals. To investigate this possibility, we have studied mice with Chd7 gene mutations to evaluate cortical development. The cortex in these mice indeed shows multiple anomalies of cortical gene expression during development, including defects of neuronal differentiation and cell migration. Both projection neurons (excitatory neurons with long axons) and interneurons (inhibitory neurons with short axons) are affected. Our findings suggest that cortical development may be perturbed in CHARGE syndrome and contribute to disease symptoms.

### **Ching-Pin Chang: Epigenetic Regulation of Neural Crest Cell Development by Brg1 and Chd7.**

Development of the cerebral vessels, pharyngeal arch arteries (PAAs) and cardiac outflow tract (OFT) requires multipotent neural crest cells (NCCs) that migrate from the neural tube to tissue destinations. However, little is known about how mammalian NCC development is orchestrated by gene programming at the chromatin level. Here we show that Brg1, an ATPase subunit of the BAF chromatin-remodeling complex, is required in NCCs to direct cardiovascular development. Mouse embryos lacking Brg1 in NCCs display immature cerebral vessels, aberrant PAA patterning, and shortened OFT. Brg1 suppresses an apoptosis factor Ask1 and a cell cycle inhibitor p21cip1 to inhibit apoptosis and promote proliferation of NCCs, thereby maintaining a multipotent cell reservoir at the neural crest. Also, Brg1 supports Myh11 expression for NCCs to develop into mature vascular smooth muscle cells of cerebral vessels. Within NCCs, Brg1 partners with a chromatin remodeler Chd7 on the PlexinA2 promoter to activate PlexinA2, which encodes a receptor for semaphorin to guide NCCs into the OFT. Our studies thus reveal a new role of Brg1 and its downstream pathways in the survival, differentiation, and migration of the multipotent NCCs, critical for mammalian cardiovascular development.

## **Adam B. Stein: Chd7 in Neural Crest-mediated Cardiac Development**

CHD7-mutation positive CHARGE patients display a range of clinical abnormalities including temporal bone defects, hearing defects, heart defects, craniofacial defects and choanal atresia. Although CHARGE Syndrome results in a seemingly diverse spectrum of congenital abnormalities, one unifying explanation is that the phenotypic traits result from abnormal neural crest cell (NCC)-mediated differentiation and/or migration. Cardiac NCCs (CNCCs) are a NCC population that migrate to the heart and great vessels where they are important for the development of the aorta and pulmonary artery from the pharyngeal arch arteries (PAAs) as well as the septation of the conotruncus into the ventricular outflow tract. We hypothesized that the absence of Chd7 in murine cardiac neural crest cells could recapitulate the congenital abnormalities seen in patients with CHARGE Syndrome. Using a Wnt1-Cre mouse model and a floxed Chd7 allele, Chd7 was conditionally deleted from neural crest cells (Wnt1-Cre) in vivo. We observed that a lack of Chd7 in Wnt1-Cre expressing neural crest cells does not compromise the ability of these cells to migrate and differentiate into normal cardiac structures. Thus, we conclude that Chd7 is not necessary for the development of neural crest-derived cardiac structures in our murine model.

## **4 - A Lot To Swallow: Understanding why individuals with CHARGE Syndrome are at high risk for choking: Awareness, Recognition, and Response - Kim Blake & Kate Beals - Palomino 6 & 7**

Children who have CHARGE Syndrome often have difficulty chewing and swallowing, which causes them to be at high risk for choking. Parents and professionals who have a better understanding of how the process of chewing and swallowing operates will be better prepared to recognize and respond to this potentially life-threatening aspect of CHARGE Syndrome.

## **5 - Behavior as Self-regulatory Adaptation, or "I can't believe my child just did that!" - Tim Hartshorne - Palomino 8 & 9**

Individuals with CHARGE often show odd, sometimes challenging, behaviors. These can lead to various psychiatric diagnoses. However, behavior is rarely random, and in fact humans actively attempt to adapt to their experience. The concept of self-regulation is a way to view "CHARGE behavior" as adaptation, and leads to avenues for intervention. This is the first of three presentations on self-regulation and intervention for behavioral challenges.

## **6 - Communication Challenges in Charge Syndrome - Daniel Choo - Palomino 10**

Children affected by Charge Syndrome (CS) pose a significant challenge to healthcare providers in terms of determining an optimal timeframe and sequence for managing communicational issues. Children are frequently affected by anomalies of the external, middle and inner ear that can cause a hearing loss and concomitant delays in auditory and verbal skill development. Compounding these delays are

associated problems of the oral cavity or oropharynx (e.g. cleft lips and palates) or the upper airway that require multiple treatments or sometimes tracheostomy tube placement that can impair voice, speech and swallowing development as well. Adding additional layers of challenges to the management plans can be a multitude of other congenital medical issues (e.g. heart anomalies) that pose major health risks and need to take priority over communicational issues. These circumstances can readily create a scenario where aspects such as hearing, speech and language can get pushed onto the back burner for so long that communicational development is beyond the typical and optimal timeframes. With increasing experience in managing children with CS, greater predictability in terms of treatment outcomes and most importantly, better interdisciplinary communication amongst managing professionals, it is possible to create a comprehensive approach and strategy that comes close to an ideal management plan for complex children with CS.

## **7 - CHARGE 101: New Family Information and Orientation - What Makes it CHARGE? How Do Sensory Deficits Change Development - Meg Hefner, Sandra Davenport, Kim Blake & Nancy Hartshorne - Dorado**

*CHARGE 101-103 is spread over Breakout Sessions 7, 15 and 20. As the Conference has grown, it has become more difficult for families coming to their first conference to get oriented - where to go, whom to talk to, how to meet each other. CHARGE 101-103 is intended to make the process a little easier. We encourage participants to ask questions of the presenters and interact with one another. We will also help guide families to other talks throughout the weekend that cover areas they are most interested in and point them to other experts to answer questions. Please feel free to come and go as your needs and interests dictate.*

In the CHARGE 101 hour, Meg will cover diagnostic criteria and medical features of CHARGE - what are the clinical diagnostic criteria and what are the other features commonly seeing in babies and children with CHARGE. Then Sandra will talk more specifically about the sensory deficits in CHARGE (especially hearing, vision and balance issues) and how those differences affect early development, with emphasis on the communication bubble.

## **8 - Grandparents Gathering - Rob Last - Moor 3**

CHARGE syndrome affects every member of the family. This meeting is only for grandparents who have a grandchild with CHARGE. It is their opportunity to have an open discussion and share experiences with other grandparents who have had to deal with the issues associated with CHARGE syndrome.

## **Friday, July 26 - 1:00-2:00 - BREAKOUT SESSION #2**

### **9 - How to Identify Pain Non-Vocally and the Relationship of Pain to Challenging Behavior - Kasee Stratton - Palomino 1 & 2**

This presentation is designed to highlight the importance of pain for individuals with CHARGE and how to identify pain non-vocally. The presentation will emphasize results from two pain studies that are the first of their kind for individuals with CHARGE. Results are presented in a manner appropriate for parents, caregivers, educators, and physicians. Specific highlights include: the variety of pain experiences (both acute and chronic), how to identify and track pain for your child, how pain impacts behavior, and strategies for reducing the pain experience.

### **10 - Balancing the Scales: Impact of Internal and External Factors on Health, Behavior and Learning - Kimberly Lauger, Kristina Manning & Megan Mogan - Palomino 3**

Moving beyond labels—such as autism— into action, this session will briefly touch on how shifts in internal and external factors change the day-to-day function of individuals. Ideas will be illustrated using the case study of one boy with CHARGE syndrome. The remainder of the session will focus on educational, and communication strategies (external factors) that effectively tipped the scale for this boy leading to improvement in all areas of the Autism Treatment Evaluation Checklist; communication, sociability, sensory and cognitive awareness, behavior and health.

### **11 - Genetics Research Updates Part #2 of 2 - Donna Martin, Seema Lalani & Yehoash Raphael - Palomino 4 & 5**

Come learn about all the latest research on CHARGE syndrome from some of the scientists doing that research. Some of the research was funded by the CHARGE Syndrome Foundation. Presentation abstracts are below.

#### **Donna Martin: Functions for CHD7, the Gene Altered in CHARGE, in Developing Cells and Tissues**

CHD7, the gene for chromodomain DNA-binding protein 7, is a common genetic cause of CHARGE Syndrome. CHD7 is highly expressed in developing human and mouse embryos, especially in stem cells and tissues that are affected in CHARGE. In order to identify the underlying mechanisms by which CHD7 regulates organ growth and development, our laboratory has generated and analyzed mice with mutations in the mouse *Chd7* gene. Mice with reduced *Chd7* function have many of the same structural and functional deficits as those observed in CHARGE; thus, detailed understanding of *Chd7* function in mice can provide critical information for designing effective therapies. We will present recent data show CHD7 functions in the development of stem cells of the ear, nose, and brain and in development of craniofacial structures. We will also discuss progress using induced pluripotent stem

cells generated from skin cells of children with CHARGE and CHD7 mutations. Together, these studies are helping to pave the way for novel, innovative strategies to develop regenerative therapies for individuals with CHARGE.

### **Seema Lalani: CHARGE and Not So CHARGE - Genetic Conditions That Overlap with CHARGE Syndrome**

CHARGE syndrome is characterized by multiple congenital anomalies including characteristic external and inner ear abnormalities, hearing dysfunction, coloboma, choanal atresia, cranial nerve abnormalities, facial palsy, and congenital heart defects. The majority of patients with CHARGE syndrome have changes/mutations in the CHD7 gene. However, the genetic basis in some children with atypical CHARGE syndrome is less clear. We completed whole exome sequencing in a subset of children who were negative for the CHD7 mutation or deletion in our study. Our data show that some of the CHD7 negative children suspected to have CHARGE syndrome have other known genetic disorders, with overlapping features of CHARGE. These syndromes will be discussed in the presentation. In addition, an overview of the genetic study results and clinical presentation of all patients will be given for the families.

### **Yehoash Raphael: Gene Therapy Induces Nerve Fiber Regeneration in the Inner Ear of Deaf Mutant Mice**

The outcome of cochlear implant therapy depends on a healthy auditory nerve. We tested whether BDNF gene transfer into the cochleae of deaf mice can influence the fate of neurons. We determined that the diameter and number of nerve fibers in the auditory epithelium were increased compared to non-treated ears, and that spiral ganglion cell density in Rosenthal's canal was also increased. The data suggest that nerve fiber regeneration treatment may augment cochlear implant therapy.

### **12 - Addressing Sensory/Oral Placement/Feeding Difficulties Associated with CHARGE Syndrome - Whitney Pimentel - Palomino 6 & 7**

Whitney will teach a unique approach to assessing the sensory system and, when it is appropriate to begin feeding and Oral-Placement Therapy techniques. The presentation will include techniques to normalize the sensory system, improve nutritional intake, and maximize oral movements necessary for safe feeding as well as improving speech clarity. The information presented will assist therapists and other educators to create a therapeutic intervention program to address the needs of these individuals.

### **13 - Why Self-stimulation Is a Good Thing and How and Why We Should Interpret It - David Brown - Palomino 8 & 9**

As the most multi-sensory impaired of syndromes, people with CHARGE are challenged to explore a range of apparently unusual behaviors in order to function effectively to satisfy their own needs. Many of these unusual behaviors seen in people

with CHARGE are attempts to compensate for sensory losses and obtain the best and most reliable information possible, both from the environment and also from their own bodies. Other of these behaviors originate as attempts to modulate arousal levels - what we would call self-regulation. All these behaviors can be characterized as 'self stimulation', which is a normal part of human behavior but often occasions extreme and persistent opposition when seen in people with CHARGE. Indeed, in the field of special education self-stimulation, or 'stimming', is often regarded as a cardinal sin to be opposed and removed at all costs. This presentation will try to clarify the role of unusual postures and self stimulation behaviors, and will encourage more careful and informed observation as the essential prelude to any intervention.

#### **14 - We Are In CHARGE - Catherine Rose - Palomino 10**

The presentation will be very interactive, fun and engaging - sharing stories from families and their experiences along the CHARGE journey. The presentation will also encourage parents to be empowered to advocate for their children - to step into the challenging role we must fulfill. We will share personal experiences as teaching lessons in challenging authority and being successful in achieving outcomes in challenging environments where parents are not trusted as experts.

#### **15 - CHARGE 102: New Family Information and Orientation - Language and Communication Options - Meg Hefner, Sandra Davenport, Kim Blake & Nancy Hartshorne - Dorado**

*See notes under Session 7.*

Communication, Communication, Communication. All learning stems from communication. Individuals with CHARGE syndrome can have enormous communication challenges, stemming from hearing and/or visual impairments, mobility issues, and medical problems. CHARGE 102 will focus on an introduction to different modes of communication available, and the importance of the earliest stimulation to encourage these modes.

In this session, we will specifically leave time for questions. Nancy, Meg, Sandy and Kim will all be available to answer questions. We, along with a few "experienced" parents (who have been to previous conferences) will address your questions and try to help guide you to other sessions or people to best address your needs.

#### **Friday, July 26 - 2:15-3:15 - BREAKOUT SESSION #3**

#### **16 - Information Central - Presentation of Posters and Opportunity to Visit With Presenters and Exhibitors - Multiple presenters - Palomino 1-5**

*This session is scheduled over Breakout Sessions #3 and 4 and over multiple rooms. You can wander through the posters and Exhibitor Area stopping wherever you like to visit with presenters and exhibitors.*

## **17 - The Challenge of Mealtimes for Children with CHARGE - Steve Rose - Palomino 6 & 7**

This presentation explores literature of the prevalence, nature and range of difficulties and the subsequent challenges presented. The features of CHARGE that relate to difficulties with mealtimes are also identified. It will outline some observations on the nature of the challenges facing children with CHARGE seen at our centre in North London. These challenges will be discussed in the context of case studies to illustrate individual challenges and possible management strategies. It is recognized that the early oral experiences of children who experience challenges eating and drinking have an impact on later development and prognosis. The involvement of cranial nerve dysfunction in CHARGE leads to a high percentage of children having eating, drinking and swallowing disorders - up to an estimate of 80% of all cases (Sanlaville and Verloes 2007). In addition there are numerous other factors and co-occurring features that impact on these difficulties, combined these present significant challenges for the child that are often seen as 'behavioural feeding issues'. Case studies will identify some of the 'mealtime behaviour' of children seen at our centre and begin to develop some understanding of the challenges facing this group of children and the sort of support that could help to overcome them. This is an area where there is less specific literature and it is hoped that this paper will begin to contribute to a greater understanding of these issues for this group of children.

## **18 - Self-regulatory Strategies for Children with CHARGE Syndrome - Maria Ramirez - Palomino 8 & 9**

The four windows of self-regulation (physiological, behavioral, cognitive, and emotional) provide the perfect areas for intervention in children with CHARGE. Although individuals with CHARGE may often use compensatory behaviors to aid in regulating their behavior, because of the presence of multisensory impairments and maladaptive patterns of behavior, positive self-regulatory strategies may at times be compromised. Using the four windows of self-regulation may prove to be an invaluable tool in understanding the function of the child's behavior, identifying the child's behavioral strengths that we can build up on, and in identifying specific self-regulatory areas to target for intervention. Strategies to enhance self-regulation in both the school and home will be presented. This presentation will be the third, preceded by Tim Hartshorne in the first hour and David Brown in the second hour.

## **19 - Fathers Forum - John Gaudin - Palomino 10**

CHARGE syndrome affects every member of the family. This meeting is only for fathers who have a child with CHARGE. It is their opportunity to have an open discussion and share experiences with other fathers who have had to deal with the issues associated with CHARGE syndrome.

**20 - CHARGE 103: New Family Information and Orientation - Breathing and Anesthesia as Critical Issues & Questions, Questions, Questions - Meg Hefner, Sandra Davenport, Kim Blake & Nancy Hartshorne - Dorado**

*See notes under session 7.*

Anesthesia, botox, sleep apnea - what's going on with breathing in CHARGE? The typical two year old with CHARGE has had more than a half dozen surgeries. Many babies and children with CHARGE have unusual reactions to anesthesia and other issues which affect breathing. Kim will present information on some of these key medical issues in infancy - things you need to know when considering various surgeries and other procedures.

Again in this session, we will leave time for your questions. Nancy, Meg, Sandy and Kim will all be available to answer questions. We will also be joined by several "experienced" parents (who have been to previous conferences). We will all answer questions and help you find the sessions and people to best address your needs.

#### **Friday, July 26 - 3:15-4:30 - BREAKOUT SESSION #4**

Information Central Continues in Palomino 1-5.

#### **Saturday, July 27 - 10:45-11:45 - BREAKOUT SESSION #5**

**21 - Intervener Services for Children Who are Deafblind: What's Happening - Linda Alsop - Palomino 1 & 2**

Exciting News! The National Resource Center for Paraeducators is now offering a National Intervener Credential for paraeducators who have training in deafblindness and who demonstrate the competencies needed to work effectively one-to-one as interveners with children and youth who are deafblind. In this presentation, this new Intervener Credential will be described, along with the process of obtaining the credential based on the successful completion of a university intervener training program, a supervised practica, and a competency-based portfolio. The role of interveners with children and youth who are deafblind will be explained, and the university intervener training programs that are available online will be described. Also, information will be presented on how parents can advocate for intervener services for their children who are deafblind through the IEP process. Finally, national efforts to establish this practice as a credible service delivery option for children and youth who are deafblind will be discussed, along with how the existence of the Intervener Credential through NRCP supports these national efforts.

**22 - Everything You Want to Know About CHARGE and Genetics - Nicole Corsten-Janssen & Conny van Ravenswaaij - Palomino 3**

CHARGE syndrome is a genetic disorder that is almost always caused by a mutation in the CHD7 gene. We start our presentation with general information on

chromosomes, DNA and gene, but we will focus on the genetics of CHARGE syndrome with special attention to the different genetic questions that parents asked us during the previous international CHARGE conferences. Like what is the CHD7 gene and what does it do? What are reasons to perform DNA analysis? What if no mutations are found with CHD7 analysis? What is the recurrence risk of CHARGE syndrome for me or my child? Is CHD7 the only gene causing CHARGE syndrome? We will save time for your personal genetic CHARGE questions.

**23 - THE SCOOP ON POOP: Is it really an art medium or fashion accessory? - Kate Beals - Palomino 4 & 5**

Fecal smearing is one of the most stressful behaviors with which many parents of children with CHARGE Syndrome must cope. Since this topic is strictly taboo in Polite Society, parents have few opportunities to discuss their experiences, frustrations, and creative solutions related to this behavior. Given information about sensory processing differences in the Olfactory and Gustatory systems, parents will understand why fecal smearing is a far different experience for their children than for themselves.

**24 - "Peaking into the Future": Expanding Opportunities to Achieve Desirable Outcomes When Students Transition from School to Adult Life - Wendy Bridgeo & Erin Selke - Palomino 6 & 7**

This presentation will highlight the importance of providing students with CHARGE syndrome including those with additional disabilities with a transition focused curriculum that starts with the end in mind. Discussion focuses on blending functional academics with the expanded core curriculum enriching career education and vocational training to increase opportunities and meaningful adult outcomes after school.

**25 - Preschoolers: Tomorrow's Teenagers: Bridging the Gap - Marguerite Bilms, Sharon Stelzer & Martha Majors - Palomino 8 & 9**

This presentation discusses observations based on the educational development of children with CHARGE Syndrome as they progress from preschool education through secondary programming. Young school-age students with CHARGE require predictability and consistency in relation to the development of communication, sensory and teaching strategies as well as curriculum. As these students progress from a preschool curriculum to a secondary curriculum, their need for a variety of strategies including sensory and educational continue to be vital. This presentation will discuss what these strategies may look like from preschool to adolescence.

**26 - Planning for the Day After: Developing Your Unique Special Needs Lifetime Care Plan - Steven Rhatigan - Palomino 10**

Caring for a loved one with unique needs can be confusing and frustrating. Taking the guesswork out of life's most difficult challenges and putting your family on

a path to a secure future requires an integrated and dynamic strategy. We will identify and discuss the key interrelated planning strategies you need to utilize if you want to assure them of the required care throughout their lifetime.

## **27 - Parent Share on Behavior - Betsy Bixler & Sheri Stanger - Dorado**

This is the first of four facilitated sessions conducted for parents on behavior, medical, education and adult issues giving parents an opportunity to share their experiences with one another. Each of the 4 sessions is a standalone session.

## **Saturday, July 27 - 1:00-2:00 - BREAKOUT SESSION #6**

## **28 - Technology for Learning, Literacy and Fun - Holly Cooper - Palomino 1 & 2**

This presentation will be an overview of assistive technology and computer applications which are both fun and useful in the home or classroom. It will include a discussion of assistive technology with an emphasis on low vision accessibility, and accessibility for users with severe disabilities. It will include a brief overview of computer low vision accessibility settings and applications, magnification devices, alternative input devices, electronic book readers. Voice output switches and medium-tech augmentative communication devices will also be discussed. Audience participation will be invited for participants to do a show and tell of iPad apps which they like using with children and youth with CHARGE.

## **29 - Neurological and Developmental Aspects of CHARGE Syndrome - Jules Constantinou - Palomino 3**

Cranial nerve impairments affecting smell, vision, facial movement, hearing, balance and swallowing are integral to CHARGE syndrome. Structural brain anomalies such as cortical dysgenesis, agenesis of the corpus callosum and hydrocephalus occur less frequently. This neurologic primer will explore the underpinnings of the developmental and motor delays, the feeding issues and the behavioral challenges and repetitive behaviors which so frequently accompany the syndrome. Similarities to attention deficit hyperactivity disorder, obsessive-compulsive disorder, tic disorder and the autistic spectrum will be highlighted. Issues related to seizure disorder will be discussed. A relaxed and interactive forum with time for questions and answers is planned.

## **30 - Bone Health...NOT a Humerus Issue - Kim Blake, Jeremy Kirk - Palomino 4 & 5**

Children with CHARGE syndrome have a number of risk factors that predispose them to poor bone health (Osteoporosis). Firstly the nutrition concerns that often starts in early childhood. Secondly, activities that are weight bearing are a challenge, and finally delayed puberty. This presentation will cover all of the above issues and will cite personal data collections from both authors to offer recommended treatments.

### **31 - Resilient Parenting - Tim Hartshorne - Palomino 6 & 7**

Parents of children with CHARGE often have moments when they feel inadequate to the task of raising their child. While other parents seem to have what it takes, they become discouraged about their own abilities. This presentation addresses how parents develop resilience in parenting their child with CHARGE. Parents come to recognize that life can have meaning, and that they can develop the courage to be imperfect, and that they can courageously raise their child.

### **32 - When Behavior Really Is Just Behavior: What To Do? - Laurie Denno - Palomino 8 & 9**

This presentation will outline the steps to take to assess challenging behavior in children with CHARGE syndrome. Parents will learn about the functions of behavior (reasons challenging behavior occurs). Treatment options and interventions will be discussed. This is a challenging and complicated enterprise. The bottom line may be to get professional help. Resources will be shared.

### **33 - National Recommendations for Improving Intervener Services: Discussion and Planning for "Next Steps" - Jay Gense & Peggy Malloy - Palomino 10**

In July 2012, the National Consortium on Deaf-Blindness (NCDB) released recommendations for improving intervener services for children who are deaf-blind (birth through age 21) in the United States. These recommendations, developed in response to a request from the U.S. Department of Education's Office of Special Education, were based on information gathered from an extensive data collection process and discussions with multiple stakeholders, including family members. This presentation will discuss the recommendations and plans for implementation.

### **34 - Parent Share on Medical Issues - Betsy Bixler & Sheri Stanger - Dorado**

This is the second of four facilitated sessions conducted for parents on behavior, medical, education and adult issues giving parents an opportunity to share their experiences with one another. Each of the 4 sessions is a standalone session.

### **35 - LAMP Words for Life: An AAC Vocabulary Program Adaptable Across Abilities, Environments, and Platforms - John Halloran - Moor 2**

Language Acquisition through Motor Planning (LAMP) is an augmentative alternative communication (AAC) approach designed to give individuals who are nonverbal or have limited verbal abilities a method of independently and spontaneously expressing themselves through the use of a speech-generating device. The key components of LAMP include a readiness to learn, engaging the learner through joint engagement, and learning language through a unique and consistent motor plan paired with an auditory signal and a natural consequence. While the LAMP approach is not device specific, the LAMP Words for Life vocabulary program has been developed to support all the components of the approach and will be the focus of this

session. There are no cognitive prerequisites for the implementation of LAMP as intervention can begin at the cause and effect level and systematically build upon the stages of natural language development. In order to maximize a student's language and communication development, one must presume the student has the potential to become a proficient communicator, provide a system that supports complex communication, but be able to teach the language in that system at a level commensurate with the learner's current abilities.

### **Saturday, July 27 - 2:15-3:15 - BREAKOUT SESSION #7**

#### **36 - Insights on Using the iPad for Young Students with CHARGE Syndrome - Gloria Rodriguez-Gil & Cristi Saylor - Palomino 1 & 2**

This presentation will demonstrate solutions, usages, advantages and disadvantages of the iPad and propose a sequence for initial learning. Video clips of examples of young students using the iPad will be used to stimulate discussion. The presentation is appropriate for parents, educators, therapists, educational technologists and technical assistance providers for young students with CHARGE syndrome who wish to learn more about using iPads to better support their young children, student users, and their educational team.

#### **37 - Endocrine Problems in CHARGE Syndrome; What Are They and How Common? - Jeremy Kirk - Palomino 4 & 5**

That children with CHARGE Syndrome have hormonal problems is reflected within the acronym: genital abnormalities (the G in CHARGE) and also a contribution to short stature. Many children, especially boys, also have problems with puberty, due to deficiency of pituitary hormones. Although it has been recognized for some time that hormonal problems are part of CHARGE syndrome, and also that there is crossover with other conditions, there is little documentation on what problems are found, and how common they are. We will present data from two very large endocrine units in the UK on over 100 patients which will show both frequency and range of hormonal problems in CHARGE Syndrome, and also their potential effects.

#### **38 - The Power of Jacob - April Bieri, Heather Dziesinski, Raylen David & Tim Hartshorne - Palomino 6 & 7**

Disability is often associated with a great deal of discouragement. How can a person with severe limitations possibly contribute to society? Jacob is a 24 year old young man who functions on the severe end of the CHARGE continuum. In this presentation, both by video and in-person, some of Jacob's caregivers will talk about his impact on their lives.

**39 - Behavior, Psychiatry and CHARGE Syndrome - Laurie Denno & John Julian - Palomino 8 & 9**

This presentation will outline Laurie's dissertation research that taught parents who were considering a psychiatric consultation how to discuss their child's challenging behavior with a psychiatrist in a specific and organized manner. Dr. Julian will discuss the process and function of a psychiatric consultation, what parents can expect during an appointment, how a diagnosis is made and how treatment is prescribed. We plan on leaving lots of time for questions and answers. This is an educational presentation.

**40 - They're Not Children Anymore: Communicating Effectively with Adult Providers - James Schwark - Palomino 10**

How can we CHARGE experts help busy adult practitioners care for our young adults with CHARGE? Much of the information on CHARGE is focused at pediatric professionals since early intervention is so crucial. However, our children with CHARGE are moving beyond pediatric practitioners to the world of adult practitioners, many of whom know little of CHARGE. This presentation calls upon experiences as CHARGE father, floor nurse and nursing instructor to present strategies for better communication with adult practitioners.

**41 - Parent Share on Education Issues - Betsy Bixler & Sheri Stanger - Dorado**

This is the third of four facilitated sessions conducted for parents on behavior, medical, education and adult issues giving parents an opportunity to share their experiences with one another. Each of the 4 sessions is a standalone session.

**Saturday, July 27 - 3:30-4:30 - BREAKOUT SESSION #8**

**42 - Physical Therapy for a Child with CHARGE Syndrome - Danielle Bushey & Mary Poblete - Palomino 6 & 7**

Physical therapy for children with CHARGE Syndrome requires extensive knowledge of the balance systems and the areas that have been compromised. An understanding of the principles of motor learning, as well as accommodations for behavioral, communication and learning challenges, are essential in a successful treatment session. Through photo and video of individuals with CHARGE Syndrome, we will be able to present the importance of physical therapy through functional activities to improve balance.

**43 - Making Sense of Behavior: The Relationship Between Sensory Input and Motor Output - Kate Beals - Palomino 8 & 9**

Individuals with CHARGE Syndrome are known to have differences in the way they register, process, and integrate information from their sensory systems. When sensory input is absent or distorted, then motor output (behavior) may appear

inappropriate to others whose sensory systems are intact. By understanding sensory processing differences in CHARGE Syndrome, parents and professionals will also achieve better understanding of the behaviors - problematic at times - that may occur as a result of these differences.

#### **44 - Family Leadership and Collaboration - Kimberly Lauger - Palomino 10**

This workshop is geared to helping families develop collaboration and leadership skills. It will include an emphasis on positive team building, tips for presenting information verbally and in writing so their message is heard. Using the topic of Interveners as an example, participants will work together to create a plan to share information with others about this topic.

#### **45 - Parent Share on Adult Issues - Betsy Bixler & Sheri Stanger - Dorado**

This is the fourth of four facilitated sessions conducted for parents on behavior, medical, education and adult issues giving parents an opportunity to share their experiences with one another. Each of the 4 sessions is a standalone session.

#### **46 - Fundraising: Big or Small We Love it All - David Wolfe - Moor 2**

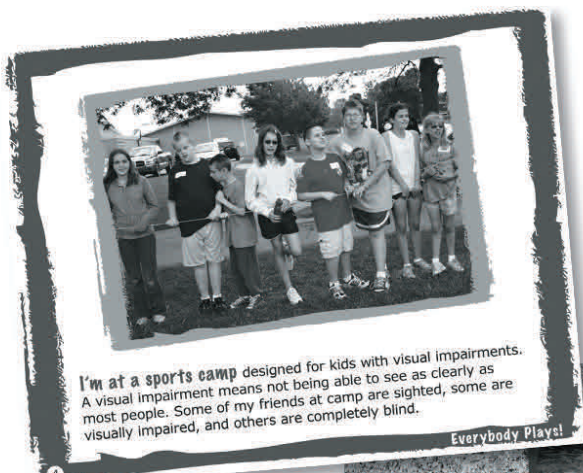
This interactive session will focus on the critical importance of fundraising for the ongoing success of the Foundation. We will highlight some interesting events and explore ways for everyone to get involved. We will also discuss the growing use of technology in fundraising as well as the more traditional approaches. Whether you are an experienced fundraiser looking to tweak your approach, or a novice looking to begin the process, this session will provide useful information. Bring your ideas, enthusiasm and questions. It Can Be Done!



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Storybook page

Listen Up! foldout page

LISTEN UP! ▼



## Paralympic Sports

**Paralympics are elite** sport events for athletes who have a disability. They emphasize the participants' athletic achievements rather than their disability. The Paralympic Games are held in the same year and city as the Olympic Games. I got to try seven Paralympic sports while at camp. Look for the Paralympic symbol on the Listen Up! pages and name the Paralympic sports I got to try.

**Paralympic Sports**

Alpine Skiing*	Powerlifting
Archery*	Rowing*
Athletics*	Sailing*
Biathlon*	Shooting
Boccia	Snow Skiing*
Cycling*	Swimming*
Equestrian*	Table Tennis
Football 5-a-side (soccer)*	Volleyball (Sitting)
Football 7-a-side (soccer)	Wheelchair Basketball
Goalball*	Wheelchair Curling
Ice Sledge Hockey	Wheelchair Dance
Judo*	Wheelchair Fencing
Para-canoe	Wheelchair Rugby
Para-triathlon*	Wheelchair Tennis

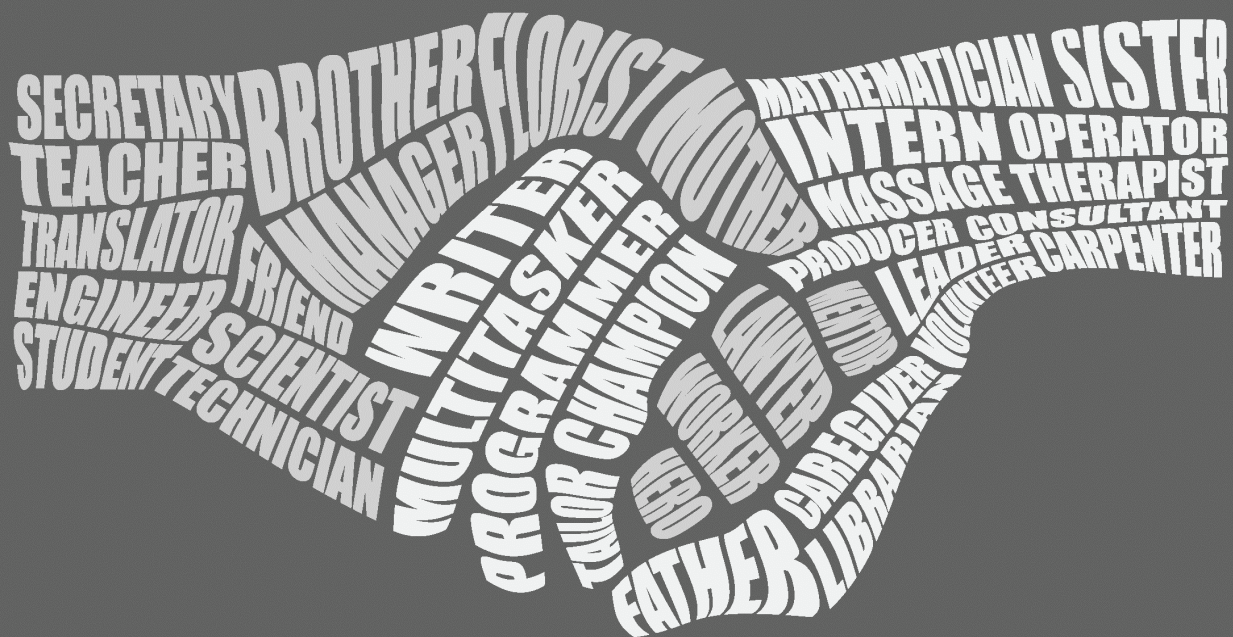
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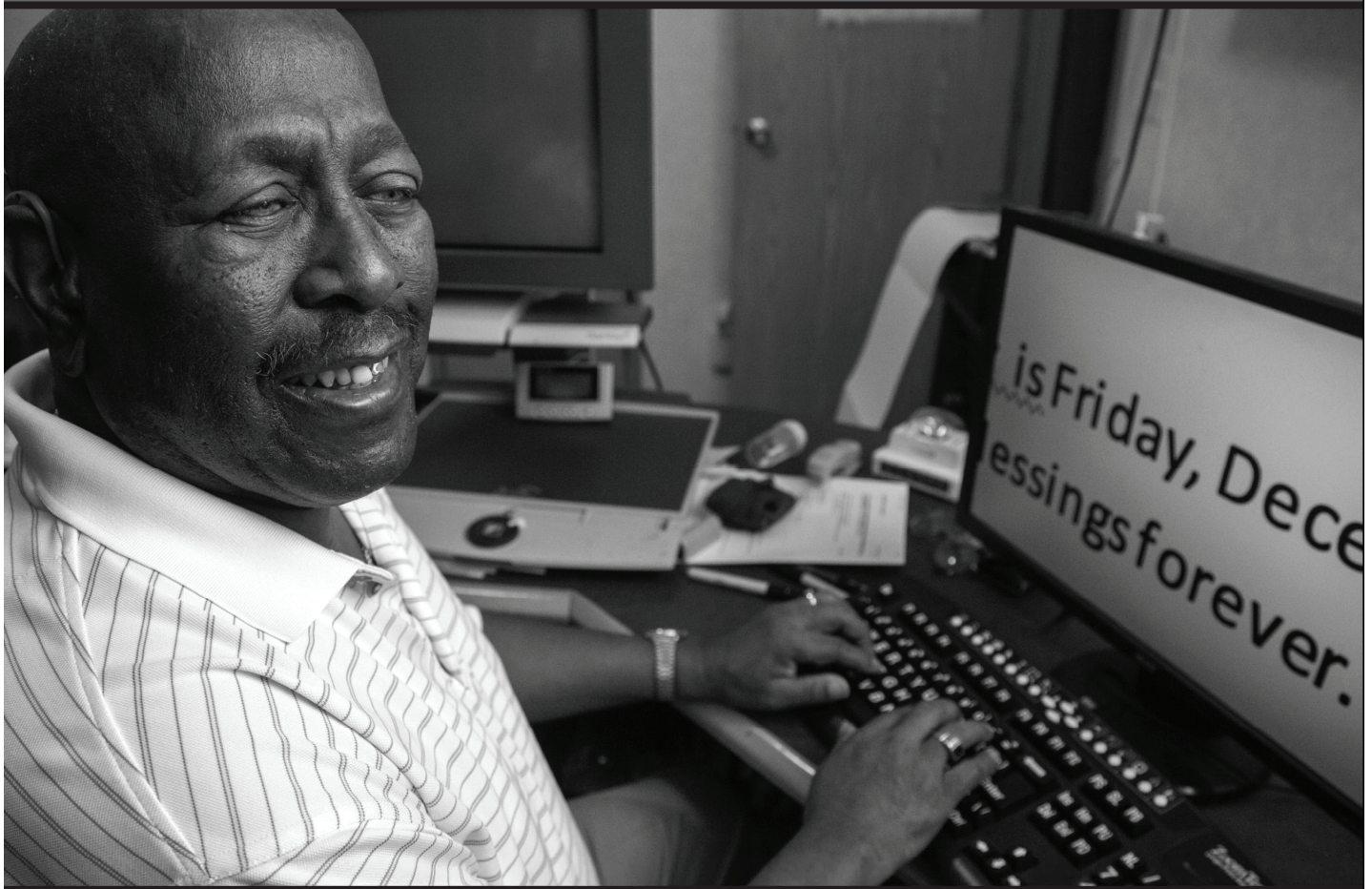
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Kathy Buckley is a five-time American Comedy Award Nominee as Best Stand-Up Female Comedienne and the winner of countless other awards for her work. She is also an actress, writer and producer, author, humanitarian, and one of the country's leading motivational speakers. An active volunteer for causes close to her heart, Kathy spends time helping numerous children's charities such as No Limits, a non-profit organization for children who are hard of hearing or deaf. A sought after speaker, she has inspired people around the nation, speaking at corporate events, conferences, and universities.

**Canadian Deafblind Association**  
14-1860 Appleby Line  
Burlington, Ontario  
L7L 7H7 Canada  
905-319-9243  
[info@cdbanational.ca](mailto:info@cdbanational.ca)  
[www.cdbanational.ca](http://www.cdbanational.ca)



CDBA is a national charitable organization created in 1975 by parents of children who were deafblind and professionals working in the field of deafblindness. Its mission encompasses awareness, support and education. Today, CDBA has a National Board of Directors with representation from across the country, a National Executive Director and six provincial chapters. Each chapter has a provincial Board of Directors supported by senior and program staff who provide a variety of services within their province to individuals who are deafblind, their families and members of the larger community.

# Sponsor, Exhibitor & Advertiser Information

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## Center for AAC and Autism

P.O. Box 1317

Wooster, OH 44691

Phone: (866) 998-1726

E-mail: [courtney@aacandautism.com](mailto:courtney@aacandautism.com)

Web: [www.aacandautism.com](http://www.aacandautism.com)

The Center for  
**AAC&Autism**

Learn. Hope. Share. Succeed.

The Center for AAC & Autism is dedicated to building awareness of the power of Augmentative and Alternative Communication (AAC) to change the lives of children with autism and other developmental disabilities, who are challenged by limited spontaneous communication skills. The Center for AAC & Autism believes that every child has the desire and the ability to communicate despite physical and neurological challenges. By providing specialized clinical training to health care professionals, teachers, and parents...empowering clients and families with education, resources, and information...and supporting clinical research, our aim is to give all children the ability to speak their mind and heart and become engaged in their world.

## Cochlear Americas

13059 E. Peakview Avenue

Centennial, CO 80111

Bobbi Scheinin, Au.D. - Group Product Manager

(303) 264-2404

(720) 940-9705 Cell

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## Notes

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# Sponsor, Exhibitor & Advertiser Information

## Compendium on CHARGE Syndrome

Multi-disciplinary and international perspectives  
Edited by Ursula Horsch & Andrea Wanka (Scheele)  
Median-Verlag von Killisch-Horn  
Germany  
[www.median-verlag.de](http://www.median-verlag.de)

This compendium on CHARGE Syndrome covers multidisciplinary and international perspectives. Special highlights are genetics, cardiology, urology, visual and hearing-related perception, phoniatrics, cochlear implantation and research on dialogue training in early educational processes as well as multi sensory impairment and deafblindness. The volume also focuses on cognitive semiotics, challenging behaviour, parental perspectives, supervision and ways of talking about Charge with affected individuals. Articles on endocrine specifics, balance, physical education and sports complete the editors' selection. Order at [amazon.com](http://amazon.com)

## **Discovery Toys**

Barbara Mueller  
5723 West Onyx Avenue  
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623-934-5669  
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Website: [www.dynavoxtech.com](http://www.dynavoxtech.com)



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DynaVox Mayer-Johnson provides speech generating devices and symbol-adapted software for children and adults with complex communication and learning needs. From portable hand-held solutions to powerful eye gaze technologies, DynaVox offers a range of communication solutions that allow all individuals to successfully communicate their needs, thoughts and emotions - regardless of age or ability.

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Enhanced Vision is the leading developer of innovative products designed specifically for individuals with low-vision conditions. Our company offers the most comprehensive line of electronic magnifying solutions including systems with HD and text-to-speech (OCR). For more information, please call or visit our website.

## Freedom Concepts Inc.

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mobility@freedomconcepts.com  
www.freedomconcepts.com



Freedom Concepts Inc. has been imagining, designing, and building a full line of adaptive bicycles, alternative seating, and mobility devices for over twenty years. Freedom Concepts products allow individuals from 18-months-old, all the way through to adulthood to discover mobility and enjoy life.

## GeneDx

Chris Lauricella  
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genedx@genedx.com  
www.genedx.com



GeneDx is a highly respected company that offers testing for more than 350 rare Mendelian disorders using DNA sequencing and deletion/duplication analysis of the associated gene(s). GeneDx also offers oligonucleotide microarray-based testing and next-generation sequencing based panels for various inherited cardiac disorders, mitochondrial disorders and neurodevelopmental disorders. Visit [www.GeneDx.com](http://www.GeneDx.com) for more information.

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# Sponsor, Exhibitor & Advertiser Information

## Helen Keller National Center

141 Middle Neck Road  
Sands Point, NY 11050  
516-944-8900  
516-944-7302 Fax  
516-944-8637 TTY  
hkncinfo@hknc.org  
hknc.org



Helen Keller National Center  
For Deaf-Blind Youths and Adults

The mission of the Helen Keller National Center is to enable each person who is deaf-blind to live and work in his or her community of choice. HKNC is the only agency that provides vocational and independent living training on a national basis exclusively to youths and adults who are deaf-blind. HKNC offers consultation and specialized services to consumers, families, and professionals, nationwide, to help them develop a greater understanding of the abilities and needs of individuals who are deaf-blind or who are experiencing combined loss of vision and hearing. Our 11 regional representatives and senior adult specialist are the first point of contact in providing information, resources and training opportunities, as well as the professionals who work with them. [www.hknc.org](http://www.hknc.org)

## iCanConnect

Helen Keller National Center  
9939 Hibert Street, Suite 108  
San Diego, CA 92131  
858-578-1600



iCanConnect promotes the National Deaf-Blind Equipment Distribution Program (NDBEDP), a federally funded program paid for by the Federal Communications Commission. It provides FREE communications equipment, assessments and training to qualified people who meet income guidelines and have combined significant hearing and vision loss, so they can stay connected with family, friends and community. Learn more at [iCanConnect.org](http://iCanConnect.org) or call 800.825.4595.

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# Sponsor, Exhibitor & Advertiser Information

## Jewish Guild Healthcare/NAPVI

15 West 65th Street

New York, NY 10023-6601

800-915-0306

Dan Callahan, Director of Children's Vision Health

[callahand@guildhealth.org](mailto:callahand@guildhealth.org)

800-562-6265

Susan LaVenture, Executive Director of NAPVI

[laventures@guildhealth.org](mailto:laventures@guildhealth.org)

[www.guildhealth.org](http://www.guildhealth.org)

# NAPVI

## JEWISH GUILD HEALTHCARE

### Vision + Health

The National Association for Parents of Children with Visual Impairments has joined Jewish Guild Healthcare (formerly the Jewish Guild for the Blind) as one of its subsidiaries. NAPVI, a non-profit, national membership organization, helps parents to find information and locate resources for their children who are blind or visually impaired and who may have additional disabilities. The Jewish Guild is a leading not-for-profit healthcare organization whose mission is to provide services designed to help people with vision loss live as independently as possible. The Jewish Guild operates national telephone support groups for parents of children who are visually impaired grouped around the eye condition of their child. One such support group is for parents of children who have CHARGE Syndrome.

## The Joys of Jennifer

**Finding Success for Your Child**

**with CHARGE Syndrome or Other Challenges**

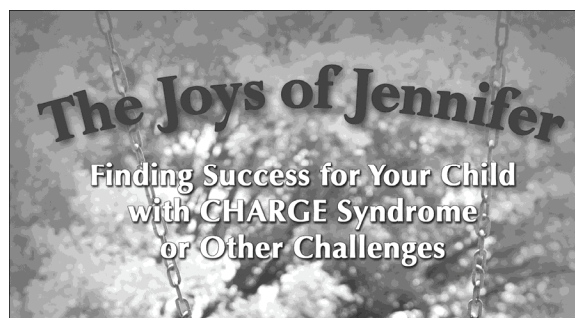
Carolyn Siewicki, Author & Mother of Jennifer,  
who has CHARGE syndrome

19879 Irving

Livonia, MI 48152

248-470-3345

[csiewicki421@aol.com](mailto:csiewicki421@aol.com)



Imagine not having a diagnosis until your child with CHARGE is five years old, with no information, internet, or outside support available. Jennifer's story will be sure to give hope and encouragement to families living the life with CHARGE. Twenty-eight years later and still strong. Meet Jennifer and get your signed copy of her book in the Exhibit Area.

We'd love to meet with you.

## Notes

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# Sponsor, Exhibitor & Advertiser Information

**Lily Voelkel Foundation**  
P. O. Box 1471  
Friendswood, TX 77549-1471  
christi.voelkel@gmail.com  
www.lilyvoelkel.com



*Lily Voelkel Foundation*  
Advocates for those DeafBlind. Everywhere.

The *Lily Voelkel Foundation* was created because of the love, courage, and strength of one little girl - Lily Korinne Voelkel. Little that is...only in size - but not in determination. Lily defeated the odds time and time again. She fought and challenged CHARGE Syndrome and continued to battle new medical complications every day.

The Lily Voelkel Foundation Mission is simple: Serve as advocates for children with CHARGE and those deafblind through targeted programs aimed at improving patient care in pediatric hospitals and at home by increasing awareness and focus while decreasing the burdens on families and medical professionals associated with the CHARGE lifestyle and other disabilities. Life is a miracle. Life is amazing if you seize opportunity...if you make meaning out of your experiences...if you grow, learn and give back to others.

## **National Family Association for Deaf-Blind (NFADB)**

141 Middle Neck Road  
Sands Point, NY 11050  
800-255-0411  
nfadb@aol.com  
www.nfadb.org  
Find us on Facebook



The National Family Association for Deaf-Blind (NFADB) is a non-profit 501(c)3 organization that has served families of individuals who are deaf-blind since 1994. NFADB exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs.

**Oticon Medical, LLC**  
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www.oticonmedicalusa.com



Oticon Medical is the manufacturer of a bone conduction hearing implant system, the Ponto. Ponto is indicated for conductive losses, mixed hearing losses and single-sided deafness. To learn more about the Ponto system, stop by the Oticon Medical exhibit during the meeting or visit us on the web at [www.oticonmedical.com](http://www.oticonmedical.com)

## Notes\_\_\_\_\_

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# Sponsor, Exhibitor & Advertiser Information

## **Perkins Training & Educational Resources Program**

Betsy McGinnity  
175 Beacon Street  
Watertown, MA 02172  
617-972-7519  
[Betsy.McGinnity@Perkins.org](mailto:Betsy.McGinnity@Perkins.org)  
[www.perkins.org](http://www.perkins.org)



The Perkins Training & Educational Resources Program (TERP) brings together information, training and educational resource functions in order to reach more people and increase the impact that these services have on the lives of people who are blind, visually impaired, deaf-blind, including those with multiple disabilities. TERP offers professional development, publications, and on-line resources for educational professionals and families. Find out more at <http://www.perkins.org/resources/>

## **Plural Publishing Inc.**

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[www.pluralpublishing.com](http://www.pluralpublishing.com)



Plural Publishing, Inc. aims to fill a space in the field of communication sciences and disorders that will help meet the needs of professionals, clinicians, professors, and students. Plural's objective, consistent with the past publishing ventures of its founders, is to meet authors and customers eye-to-eye and reduce the "ivory tower mentality" from the professional publishing world. Plural Publishing prioritizes the intellectual growth of the disciplines it serves and strives to improve and advance these fields through its publications.

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[www.seedlings.org](http://www.seedlings.org)  
[info@seedlings.org](mailto:info@seedlings.org)  
800-777-8552



Seedlings Braille Books for Children is a non-profit organization based in Michigan, dedicated to increasing the opportunity for literacy by providing high quality, low-cost children's literature in braille to children worldwide. We have over 1,100 book titles available in our 2011 catalog from classics to bestsellers for children ages 0-14. Since 1984, Seedlings has been bringing the joy of reading to countless blind children, helping them to read and succeed. For more information visit [www.seedlings.org](http://www.seedlings.org) or contact us at 800-777-8552.

## Sorenson Communications

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[www.sorenson.com](http://www.sorenson.com)



Sorenson Communications is the leading manufacturer and provider of videophones customized for the deaf and hard-of-hearing. To date, Sorenson has developed four videophones: the Sorenson VP-100® and Sorenson VP-200®, designed specifically for the deaf using the latest video communication and unique features, the D-Link i2eye videophone, intended for the mass market and the new ntouch VP, our newest innovation built with industry-leading videophone technology.

SVRS® empowers the deaf and hard-of-hearing community to communicate with both, deaf and hearing family, friends or business contacts using video relay service. This free, 24-hour service empowers you to place and receive calls with a professional American Sign Language (ASL) interpreter via a videophone and a high-speed internet connection. In addition, the services enable hearing callers to contact deaf or hard-of-hearing individuals as well.

## Sweet Spirit Productions

Janet & Sandy Buller  
Pattison, TX 77466  
281-375-5377  
[www.sspwse.com](http://www.sspwse.com)



Sweet Spirit Productions has been serving the special needs community since 2004. We specialize in films and photography of all the important moments of your life - imagery that touches your heart and moves your spirit. We offer everything from family biographies to portraits to wedding and special event videos. Our award-winning, family oriented images reflect all of God's beauty. Available worldwide. Visit [BullerProductions.com](http://BullerProductions.com) for editorial, commercial and lifestyle imagery.

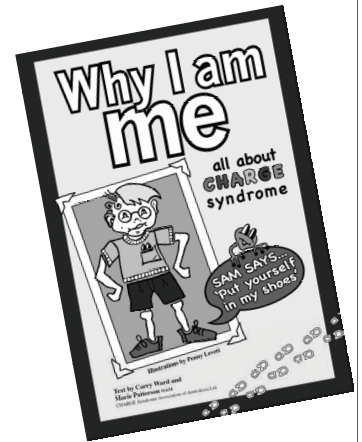
# Sponsor, Exhibitor & Advertiser Information

## Why I Am Me? A Book All About CHARGE syndrome

Carry Ward & Marie Patterson, Authors  
[www.chargesyndrome.org.au](http://www.chargesyndrome.org.au)

Why I Am Me is a story about a boy called Sam who has CHARGE Syndrome and his friend Jess. As the story progresses Jess learns about CHARGE Syndrome and the challenges Sam faces on a day-to-day basis. Written by Carry Ward and Marie Patterson with illustrations by Penny Levett, the idea for this book was sparked by questions asked by a young person with CHARGE. As a result this book is written from a unique perspective. The story is supported by medical information, diagrams and photographs of children and young persons with CHARGE. It includes simulation activities to provide greater insight into what it might be like to have CHARGE.

Books are available for purchase at this conference or purchase online from [www.chargesyndrome.org.au](http://www.chargesyndrome.org.au)



## **WonderBaby.org**

Amber Bobnar  
42 Frank Street  
Watertown, MA 02472  
617-923-1241  
[amber@wonderbaby.org](mailto:amber@wonderbaby.org)  
[www.wonderbaby.org](http://www.wonderbaby.org)



WonderBaby.org is an online community supporting parents of babies, toddlers and young children who are visually impaired or multiply disabled.

### **Help your child:**

- Explore their world
- Develop social skills
- Learn and grow

## **Yuni Headphones**

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[www.yuniheadphones.com](http://www.yuniheadphones.com)



Yuni is the first true stereo headphone made for people with unilateral deafness or hearing loss. The Yuni uses a revolutionary new stereo technology (patent pending) that places both stereo channels in a single earpiece, but with two separate speakers instead of just one -- one above, and one below the ear opening. With the Yuni, you can hear and distinguish the two channels, identifying which sound is coming from which speaker. You can finally hear true stereo panning as the sound moves from one channel to the other! If you're a unilaterally deaf music-lover who has never experienced these effects through headphones, it may be difficult to appreciate how much your music will come alive when it's played the way it was meant to be enjoyed...in stereo.



(\*) Lower Level **E** Elevator

1. Lobby
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3. Bell Desk
4. Concierge Desk
5. Golf Concierge/Car Rental
6. Princess Coffee Shop & Retail Market
7. Silver Saguaro Gallery

8. Prickly Pear Clothierie
9. Bourbon Steak by Michael Mina
10. Princess Plaza
11. Plaza Bar
12. Princess Falls(\*)
13. Princess Ballroom & Conference Center
14. New Palomino Ballroom & Conference Center

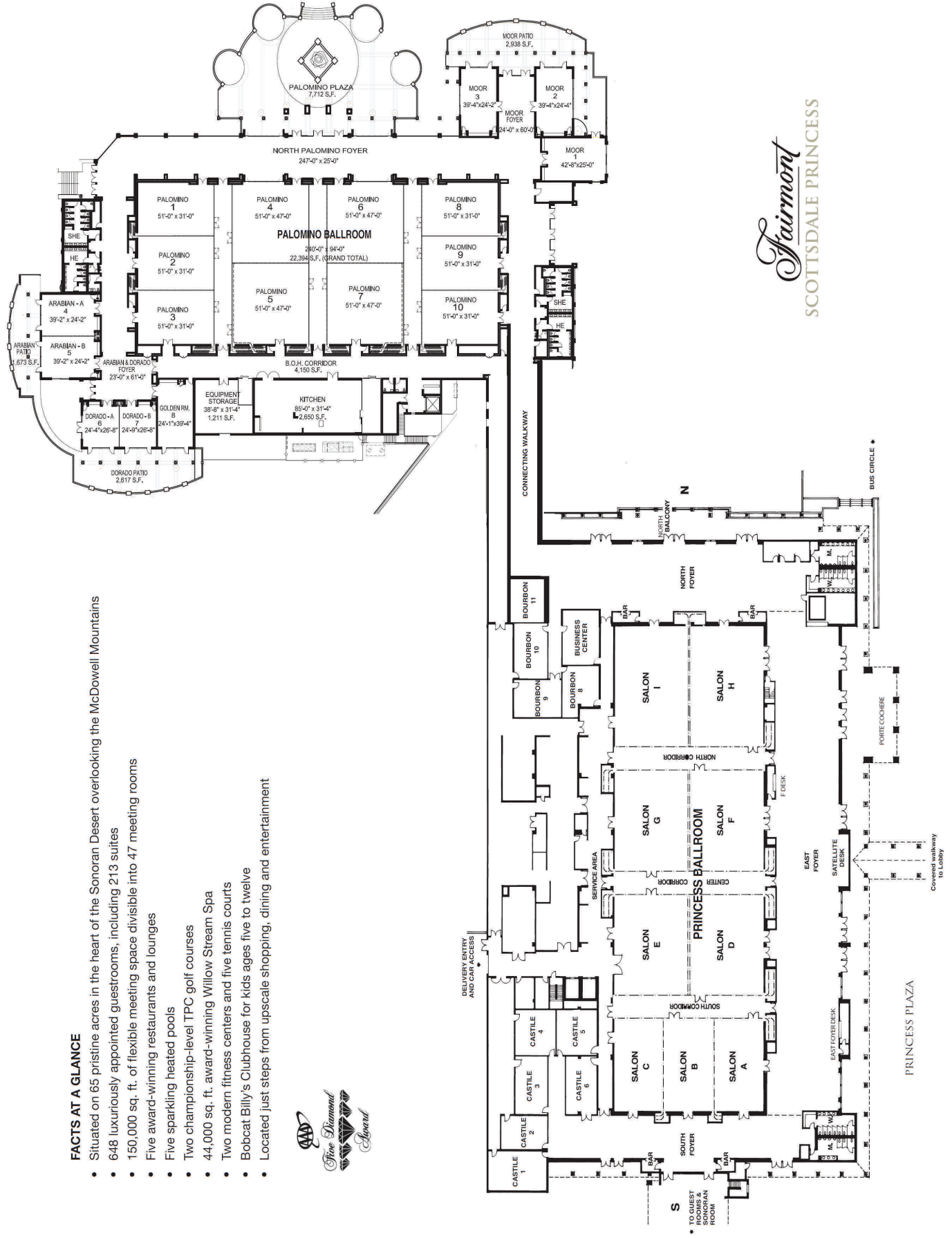
15. La Hacienda with Patio Seating
16. Well & Being at Willow Stream
17. Hacienda Plaza & Trellis
18. Cactus Garden
19. Well & Being Salon
20. Casita Pool & Jacuzzi
21. South Pool(\*)

22. Ironwood American Kitchen(\*)
23. Cabana Cafe/Mist(\*)
24. Bobcat Billy's Clubhouse(\*)
25. Fairmont Fitness Center(\*)
26. Fragrance Garden
27. Ironwood Circle
28. Sonoran Splash

29. Sport Court & Playground
30. East Pool & Frieze
31. The Grill at TPC (free shuttle from front drive)
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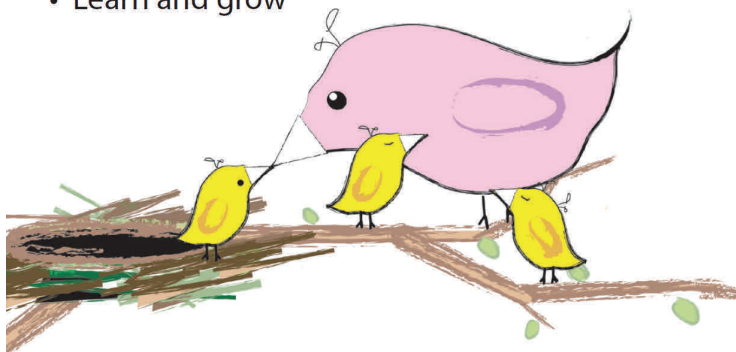
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# WonderBaby.org

WonderBaby.org is an online community supporting parents of babies, toddlers and young children who are visually impaired or multiply disabled.

## Help your child:

- Explore their world
- Develop social skills
- Learn and grow



**PATHS TO LITERACY**

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Just go to [PerkinseLearning.org](http://PerkinseLearning.org)

## PathsToLiteracy.org

Paths to Literacy now offers a way to earn Continuing Education credits or Professional Development Points (PDPs)! Teachers are invited to post strategies related to any aspect of literacy for children who are blind or visually impaired, including those with additional disabilities. We're looking for practical ideas that have worked well for you related to writing, emergent literacy, braille, large print, objects, auditory strategies, or anything that you would like to share with others.

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Cochlear provides the Nucleus® Cochlear™ Implant and the Baha® System for people with different types of hearing loss. Talk to a Cochlear Concierge to understand what's right for your child ... call 800-483-3123 or email [Concierge@Cochlear.com](mailto:Concierge@Cochlear.com)



Hear now. And always